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Original Study

Perception of the Quality of Communication With Physicians Among Relatives of Dying Residents of Long-term Care Facilities in 6 European Countries: PACE Cross-Sectional Study

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A B S T R A C T

Keywords:

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 physician
 relative

Objective: To examine how relatives evaluate the quality of communication with the treating physician of a dying resident in long-term care facilities (LTCFs) and to assess its differences between countries.

Design: A cross-sectional retrospective study in a representative sample of LTCFs conducted in 2015. Relatives of residents who died during the previous 3 months were sent a questionnaire.

Settings and participants: 761 relatives of deceased residents in 241 LTCFs in Belgium, England, Finland, Italy, the Netherlands, and Poland.

Methods: The Family Perception of Physician-Family Communication (FPPFC) scale (ratings from 0 to 3, where 3 means the highest quality) was used to retrospectively assess how the quality of end-of-life communication with treating physicians was perceived by relatives. We applied multilevel linear and logistic regression models to assess differences between countries and LTCF types.

Results: The FPPFC score was the lowest in Finland (1.4 ± 0.8) and the highest in Italy (2.2 ± 0.7). In LTCFs served by general practitioners, the FPPFC score differed between countries, but did not in LTCFs with on-site physicians. Most relatives reported that they were well informed about a resident's general condition (from 50.8% in Finland to 90.6% in Italy) and felt listened to (from 53.1% in Finland to 84.9% in Italy) and understood by the physician (from 56.7% in Finland to 85.8% in Italy). In most countries, relatives assessed the worst communication as being about the resident's wishes for medical treatment at the end of life, with the lowest rate of satisfied relatives in Finland (37.6%).

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Conclusion: The relatives' perception of the quality of end-of-life communication with physicians differs between countries. However, in all countries, physicians' communication needs to be improved, especially regarding resident's wishes for medical care at the end of life.

Implications: Training in end-of-life communication to physicians providing care for LTCF residents is recommended.

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In palliative care, the alliance between the treating physician and patients' relatives plays a special role since the latter, in most cases, must make difficult decisions concerning treatment when a dying person has fluctuating levels of consciousness, advanced dementia, or is comatose.^{1–4} A Canadian group of experts defined end-of-life (EOL) communication and decision making as a clinical interaction (among patients, family members, and clinicians) that includes discussions on death and dying.⁵ They propose it is not limited to the terminal stages of dying but includes discussions about planning future care with chronically ill patients or healthy people in case of unexpected fatal illnesses. The main goal of EOL communication is to create a shared understanding about a patient's values and treatment preferences and to plan care that is consistent with them.⁵ Relatives of terminally ill patients highlight that emotional and psychological support, along with good communication with the treating physician, are of equal importance to the provision of the best medical care.^{6–8} Unfortunately, relatives of the residents of long-term care facilities (LTCFs) tend to rate the overall quality of care provided by physicians lower as compared to care by nursing staff.⁹

Research on the perception of quality of EOL communication by relatives of dying LTCF residents is scarce¹⁰ and mostly conducted in 1 or 2 countries,^{10–14} hence it is inadequate for multinational comparisons.¹⁵ In the PACE Project (Palliative Care for Older People), we had an opportunity to study this issue in 6 European countries.

The aim of this article was to show how relatives of deceased LTCF residents evaluate the quality of EOL communication with treating physicians while analyzing differences between countries and between LTCFs with on-site physicians (employed by the institution) and institutions served by off-site family doctors or general practitioners (GPs).

Methods

Study Design

In 2015, a questionnaire-based cross-sectional study was carried out in LTCFs in 6 European countries: Belgium, England, Finland, Italy, the Netherlands, and Poland. An LTCF was defined as an institution that provides nursing and care services for its residents 7 days a week, 24 hours a day.¹⁶ We conducted a retrospective study of the opinions of the relatives of deceased residents. Therefore, we included only LTCFs with at least 1 death of a resident reported in the period of 3 months before the researcher's visit. For this article, we distinguished 2 types of LTCFs depending on physician availability:

- on-site (eg, nursing home doctor, elderly care physician, or other physician employed by the LTCF) and
- off-site (eg, family doctor or GP visiting residents on a regular basis and on call).

To ensure representativeness of the sample selection, stratified sampling was used, taking into account region, type of facility, and its size (number of beds); the protocol of the study is described elsewhere.¹⁶

Data Collection and Study Population

In each participating LTCF, residents who died within the past 3 months were identified, and questionnaires asking about quality of EOL care and their dying were sent to (1) the LTCF manager, (2) the staff member most involved in care, (3) the treating physician, and (4) the most involved close relative (family or friend). We identified 1707 deceased residents in 322 LTCFs (Figure 1). We then located the relatives of 1455 deceased residents and sent them a questionnaire asking how they perceived the communication about the end of life with the treating physician. In total, 840 relatives responded to the study invitation (response rate = 58.1%). From the analyses, we excluded the opinions of those relatives who had more than 1 missing answer to 7 items of the Family Perception of Physician-Family Communication (FPPFC) scale.¹³ Finally, we

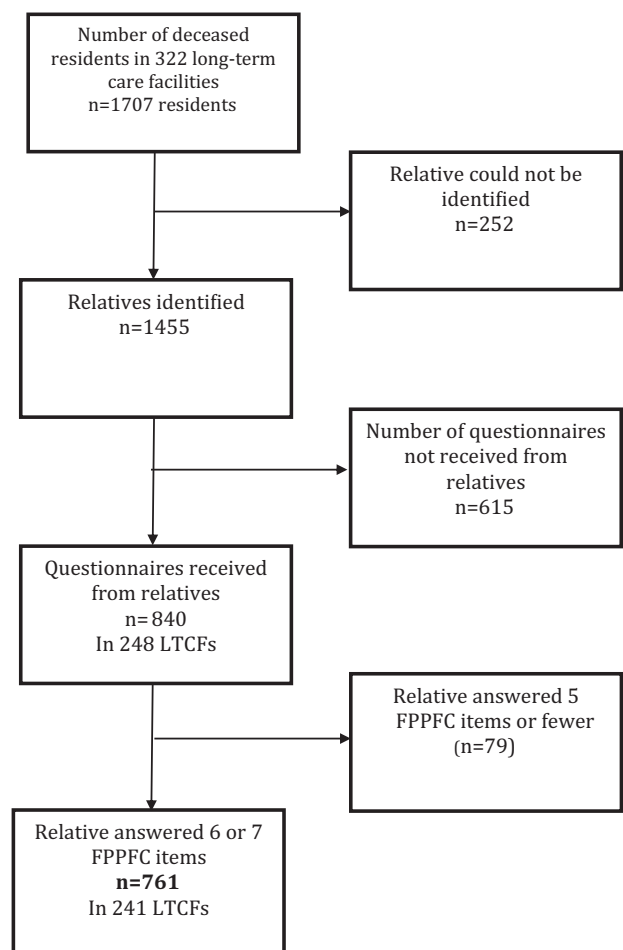


Fig. 1. Flowchart of a sample of relatives of deceased residents of long-term care facilities in 6 countries.

Table 1

Characteristics of Relatives (n = 761), Deceased Residents of Long-term Care Facilities (n = 761), and the Treating Physicians (n = 354) in 6 European Countries

Characteristics of the Study Sample	Belgium (n = 197)	Finland (n = 128)	Italy (n = 106)	The Netherlands (n = 185)	Poland (n = 120)	England (n = 25)	P*
Relative Characteristics (n = 761)							
Age, y, mean (SD)	61.2 (9.3)	59.7 (11.8)	54.7 (10.5)	61.7 (10.2)	56.4 (12.2)	61.2 (11.5)	<.001
Sex, female, n (%)	117 (60.0)	82 (65.6)	56 (55.4)	124 (67.8)	79 (68.1)	17 (68.0)	.23
Relationship with the deceased resident, n (%)							
Spouse or partner	17 (8.7)	22 (17.5)	6 (5.7)	25 (13.7)	9 (7.5)	2 (8.0)	<.001
Child	146 (74.5)	79 (62.7)	55 (51.9)	121 (66.1)	70 (58.3)	17 (68.0)	
Other	33 (16.8)	25 (19.8)	45 (42.5)	37 (20.2)	41 (34.2)	6 (24.0)	
Lived together with the resident before her or his admission to LTCF (n,%)	24 (12.2)	34 (26.8)	32 (30.2)	25 (13.5)	46 (38.3)	4 (16.0)	<.001
Time spent with the resident during the last week of her or his life, n (%)							
0–14 h	41 (20.8)	65 (51.2)	54 (50.9)	30 (16.2)	81 (68.1)	9 (36.0)	<.001
>14 h	156 (79.2)	62 (48.8)	52 (49.1)	155 (83.8)	38 (31.9)	16 (64.0)	
EQ-VAS, 0–100, median (Q ₁ –Q ₃)	80 (70–90)	83.5 (73–91)	90 (70–95)	85 (75–90)	80 (60–90)	80 (60–95)	<.001
Emotional burden, 0–10, median (Q ₁ –Q ₃)	8 (7–9)	8 (5–9)	8 (6–9)	8 (5–9)	8 (5–10)	7 (3–8)	<.001
Resident characteristics (n = 761)							
Age at time of death, y, mean (SD)	87.1 (7.1)	85.0 (9.0)	84.3 (8.1)	86.1 (8.3)	82.4 (9.7)	87.7 (8.2)	<.001
Sex, female, n (%)	120 (65.6)	85 (69.7)	75 (70.8)	115 (67.6)	84 (70.6)	21 (84.0)	.56
Resident had dementia [†] , n (%)	108 (56.8)	106 (84.1)	68 (68.0)	101 (62.7)	79 (68.7)	11 (61.1)	.003
Cancer was the cause of death, n (%)	14 (7.6)	18 (14.4)	10 (10.1)	15 (9.4)	6 (5.4)	1 (5.3)	.21
BANS-S score [‡] , mean (SD)	18.7 (5.0)	19.6 (4.2)	21.9 (4.1)	17.4 (4.5)	22.7 (4.3)	17.9 (3.6)	<.001
Dying resident was provided palliative care by a physician, n (%)	108 (66.7)	60 (53.6)	11 (12.0)	97 (74.0)	8 (9.1)	5 (41.7)	<.001
Number of physician visits during the last week of resident's life, n (%)							
<3	78 (61.4)	47 (47.0)	49 (59.0)	37 (32.7)	31 (32.6)	7 (87.5)	<.001
≥3	49 (38.6)	53 (53.0)	34 (41.0)	76 (67.3)	64 (67.4)	1 (12.5)	
Physician was the same as the one caring for the resident before admission to LTCF, n (%)	86 (67.7)	25 (24.8)	41 (48.8)	32 (27.6)	10 (10.2)	2 (25.0)	<.001
Type of facility in which resident lived, n (%)							
With on-site physician	NA	NA	30 (28.3)	81 (49.4)	83 (69.2)	NA	.24
With off-site physician	183 (100)	124 (100)	76 (71.7)	83 (50.6)	37 (30.8)	25 (100)	
Physician characteristics (n = 354)							
Age, y, mean (SD)	53.2 (11.2)	44.6 (10.4)	55.8 (8.0)	48.7 (10.9)	55.5 (13.2)	43.9 (9.3)	<.001
Sex, female, n (%)	32 (24.8)	57 (55.9)	28 (33.3)	62 (53.4)	66 (68.0)	3 (37.5)	.002
Work experience, y, median (Q ₁ –Q ₃)	28 (21–35)	15 (10–29)	21 (16–27)	16 (8–25)	14 (6–25)	12 (8–20)	<.001

BANS-S, Bedford Alzheimer Nursing Severity Scale; EQ-VAS, EuroQol visual analog scale; SD, standard deviation.

Missing values regarding characteristics of relatives: age = 59 years, sex = 19, relationship with the deceased resident = 5, lived together with resident before he or she was admitted to LTCF = 1, time spent with the resident during the last week of his or her life = 2, general health score = 14, emotional burden = 7.

Missing values regarding characteristics of residents: age at time of death = 46 years, sex = 36, resident had dementia = 51, cancer was a cause of death = 62, functional status 1 month before death = 126, dying resident was provided palliative care by a physician = 164, number of physician's visits in the last week of resident's life = 235, type of facility in which resident lived = 39, physician was the same as the one caring for the resident before admission to LTCF = 227.

Missing values regarding characteristics of physician: age = 6 years, gender = 2, work experience = 8.

*Generalized mixed model reporting P value for country as a fixed effect, $\alpha = 0.05$.[†]Resident had dementia in the opinion of the physician and/or care staff.[‡]Functional status 1 month before death (BANS-S score): a higher BANS-S score represents a lower functional status.

analyzed the opinions of 761 relatives of deceased residents in 241 LTCFs.

Measurements

The perception of EOL communication with physicians by relatives was assessed using the FPPFC scale.¹³ The FPPFC scale consists of 7 items (Table 2), each scored on a 4-point Likert scale, from 0 to 3 leading to an FPPFC score equal to the mean of values of these items. The higher the score, the better the perceived quality of communication. Originally, the scale was developed in the End of Life in Residential Care and Nursing Homes study. It showed a high internal consistency (Cronbach alpha = 0.96)¹³ and was determined to be one of the best available.^{17,18} The questionnaires used in the PACE project contained several other questions. The data concerning the relatives included information about their age, sex, general health status (scored 0–100 on the EuroQol visual analog scale), relationship with the deceased residents, and their involvement in care of the resident (time spent with resident during the last week of her or his life, emotional burden related to the last phase of the resident's

life). The data about residents were obtained from the LTCF manager (age, sex), the nurse (cognitive functioning assessed with Bedford Alzheimer Nursing Severity Scale; palliative care provision by a treating physician), and the physician (number of physician's visits in the last week of the resident's life, whether the physician was the same person as the one caring for the resident before admission to the LTCF). The data regarding the primary cause of death and whether the resident had dementia were based on the clinical judgment of the physician or the nurse assessment. The data describing the physicians included age, sex, and professional experience (Table 1).

Research Ethics

The research teams in all participating countries obtained ethical approval from their respective ethics committees. The teams from the Netherlands and Italy were exceptions, as the consulted ethics committees in these countries judged that no formal ethics approval was needed and provided waivers.

Table 2
Perception of Physician-Relative Communication by the Relatives of Deceased Residents of Long-term Care Facilities: Differences Between Countries in the FPPFC Score (n = 761)

Item	Family Perception of Physician-Family Communication (FPPFC) [†]	BE (n = 197)	FI (n = 128)	IT (n = 106)	NL (n = 185)	PL (n = 120)	EN (n = 25)	P*
1	The physician always kept relative informed about resident's condition	2.0 (1.0)	1.4 (1.0)	2.4 (0.8)	2.1 (0.8)	1.9 (0.9)	1.8 (1.1)	<.001
2	The relative always received information from the physician about what to expect while resident was dying	1.7 (1.0)	1.8 (1.1)	2.2 (0.8)	2.0 (0.8)	1.7 (0.9)	1.8 (1.0)	.001
3	The physician always helped relative to understand what they might expect while resident was dying	1.7 (1.0)	1.1 (0.9)	2.3 (0.8)	2.0 (0.8)	1.8 (0.9)	1.7 (0.9)	<.001
4	The physician always spoke to the relative/resident about resident's wishes for medical treatment at the end of life	1.6 (1.0)	1.1 (1.0)	1.9 (1.1)	2.0 (0.8)	1.6 (0.9)	2.0 (0.8)	<.001
5	The relative always had the opportunity to ask the physician questions about care for the resident	2.0 (0.9)	1.5 (1.0)	2.3 (0.7)	2.2 (0.8)	2.0 (0.9)	2.0 (0.9)	<.001
6	The physician always listened to what the relative/resident had to say about resident's medical treatment and end-of-life care	2.0 (0.9)	1.5 (1.0)	2.3 (0.8)	2.2 (0.8)	1.9 (0.9)	2.0 (0.8)	<.001
7	The physician always understood what the relative/resident were going through	2.0 (0.9)	1.5 (1.0)	2.3 (0.8)	2.2 (0.8)	1.9 (0.9)	1.9 (0.9)	<.001
	Total score	1.9 (0.8)	1.4 (0.8)	2.2 (0.7)	2.1 (0.7)	1.8 (0.8)	1.9 (0.9)	<.001

BE, Belgium; EN, England; FI, Finland; IT, Italy; NL, the Netherlands; PL, Poland.

Values are mean (standard deviation). Missing data: item 1 = 0, item 2 = 4, item 3 = 12, item 4 = 12, item 5 = 2, item 6 = 0, item 7 = 4.

*Generalized linear mixed model reporting P value for country as a fixed effect, $\alpha = 0.05$.

[†]A higher FPPFC score represents better quality of communication.

Analysis

Descriptive statistics were applied to characterize relatives, deceased residents, and their treating physicians. We used multilevel models (linear and binary or multinomial logistic) to assess differences between countries (Table 1). We applied multilevel linear regression models to compare the mean FPPFC scores between countries (Table 2 and Supplemental Figure 1) and 2 LTCF types: with the physician on-site or off-site (Supplemental Table 1). Next, we compared relatives' opinions measured with the FPPFC scale in terms of numbers of relatives who "strongly agreed" or

"agreed" vs "disagreed" or "strongly disagreed" on the quality of their communication with the physicians. We combined these answers and used them in multilevel binary logistic models to assess differences between countries (Table 3) and the 2 LTCF types mentioned above (Supplemental Table 2). In each multilevel model, country was included as a fixed effect. Because of the interaction between country, LTCF type, and FPPFC score, we calculated the mean FPPFC score for each country in strata (LTCF type) and compared differences using Games-Howell test (Figure 2). All the analyses were performed with SPSS 25. An alpha level of <.05 defines statistical significance.

Table 3
Percentage of Relatives of Deceased Residents of Long-term Care Facilities Who "Strongly Agreed" or "Agreed" With Single Items of the FPPFC Scale: Differences Between Countries (n = 761)

Item	Family Perception of Physician-Family Communication (FPPFC)	BE (n = 197)	FI (n = 128)	IT (n = 106)	NL (n = 185)	PL (n = 120)	EN (n = 25)	P*
1	The physician always kept relative informed about resident's condition	147 (74.6)	65 (50.8)	96 (90.6)	154 (83.2)	87 (72.5)	17 (68.0)	<.001
2	The relative always received information from the physician about what to expect while resident was dying	122 (61.9)	85 (66.9)	88 (83.8)	138 (75.4)	77 (64.2)	16 (64.0)	<.001
3	The physician always helped relative to understand what they might expect while resident was dying	119 (62.0)	43 (34.7)	89 (84.0)	138 (75.8)	79 (65.8)	16 (64.0)	<.001
4	The physician always spoke to the relative/resident about resident's wishes for medical treatment at the end of life	104 (53.9)	47 (37.6)	68 (64.8)	138 (75.0)	62 (53.0)	19 (76.0)	<.001
5	The relative always had the opportunity to ask the physician questions about care for the resident	147 (74.6)	69 (53.9)	93 (87.7)	157 (85.3)	94 (78.3)	19 (79.2)	<.001
6	The physician always listened to what the relative/resident had to say about resident's medical treatment and end-of-life care	146 (74.1)	68 (53.1)	90 (84.9)	156 (84.3)	87 (72.5)	19 (76.0)	<.001
7	The physician always understood what the relative/resident were going through	151 (77.4)	72 (56.7)	91 (85.8)	157 (84.9)	87 (73.1)	18 (72.0)	<.001

BE, Belgium; EN, England; FI, Finland; IT, Italy; NL, the Netherlands; PL, Poland.

Values are n (%). Missing data: item 1 = 0, item 2 = 4, item 3 = 12, item 4 = 12, item 5 = 2, item 6 = 0, item 7 = 4.

*Generalized logistic mixed model reporting P value for country as a fixed effect, $\alpha = 0.05$.

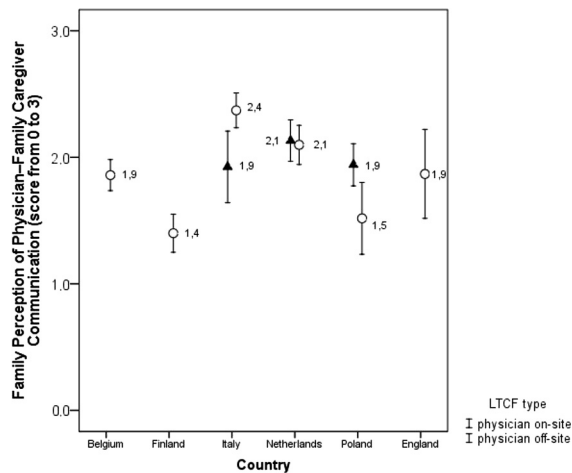


Fig. 2. Perception of physician-relative communication by the relatives of deceased residents of long-term care facilities: differences between countries and types in the FPPFC score.

Note. Figure presented as mean and 95% CI. Statistically significant differences calculated using the Games-Howell test, $\alpha = 0.05$: Finland-Belgium, the Netherlands (off-site)-Belgium, the Netherlands (off-site)-Finland, Italy (off-site)-Finland, Poland (off-site)-the Netherlands (off-site), Poland (off-site)-Italy (off-site) and the Netherlands (on-site)-Finland, Italy (on-site)-Finland, Poland (on-site)-Finland, Poland (on-site)-the Netherlands (off-site), Poland(off-site)-Italy (on-site). Due to the low number of answers from England ($n = 25$) we had to limit pairwise comparison to five countries.

Results

Characteristics of the Relatives of Deceased LTCF Residents

The mean age of relatives ranged from 55 years in Italy to 62 years in the Netherlands (Table 1). More than half of the respondents in all countries were a child of the deceased resident. The percentage of relatives living with the resident before admission to the LTCF was the highest in Poland and the lowest in Belgium. In contrast, their time involvement in caring for the resident was almost the highest in Belgium (79.2% relatives devoted more than 14 hours during the resident's last week of life) and the lowest in Poland (31.9%). The relatives in Italy assessed their health to be the best (on the EuroQol visual analog scale) and the worst in Belgium, Poland, and England. The level of emotional burden reported by relatives associated with care for the resident in the last phase of life was the lowest in England and the highest in Belgium.

Characteristics of the Deceased LTCF Residents

Residents' mean age at death was lowest in Poland (82 years) and highest in England (88 years) (Table 1). Their physical condition (at 1 month before death) measured with the Bedford Alzheimer Nursing Severity Scale was also the worst in Poland and the best in the Netherlands and England. Prevalence of dementia among them was high in all countries, ranging from 56.8% in Belgium to 84.1% in Finland. In contrast, residents dying of cancer were a minority in all countries. The percentage of residents who were visited by a treating physician more than twice during the last week of their life was the highest in Poland (67.4%) and in the Netherlands (67.3%), and the lowest in England (12.5%). However, the number of dying residents who were provided with palliative care by their treating physician was the highest in Belgium and the Netherlands, and the lowest in Poland and Italy. In Belgium, the majority (in Italy almost half) of residents were treated by the same physician who was caring for them before admission to the LTCF. It was quite the opposite in Poland, where almost 90% of residents were cared for by a different physician.

Data About the Physicians Treating Dying LTCF Residents

Physicians differed significantly between countries, with a mean age of 44 to 56 years (with the youngest in England and the oldest in Italy and Poland) and median number of work years (from 12 to 28 in England and Belgium, respectively) (Table 1).

FPPFC Score in 6 European Countries

The mean FPPFC score ranged between 1.4 (± 0.8) in Finland and 2.2 (± 0.7) in Italy (Table 2). In the pairwise comparisons, we found statistically significant differences between the country pairs (Supplemental Figure 1). There were country-related differences on each individual item of the FPPFC scale. In most countries, relatives perceived the EOL communication with a resident's physician as the best with respect to provision of information on the resident's condition (item 1), feeling of being listened to (item 6), and feeling of being understood by the physician (item 7). The aspects of communication with physicians assessed as the lowest by the relatives concerned conversations on resident's wishes regarding treatment near death (item 4) and physician's assistance in understanding what the relatives may or should expect if the resident were to die (item 3) (Table 2).

Percentages of relatives reporting that the physician had always kept them informed about the resident's health condition was the lowest in Finland (50.8%) and the highest in Italy (90.6%). Similarly, the number of relatives who indicated that they always had the opportunity to ask the physician questions concerning care for the resident was the highest in Italy (87.7%) and the lowest in Finland (53.9%). Barely one-third of relatives from Finland confirmed that the physician explained what they should expect regarding the dying process. Only slightly more (37.6%) had had the opportunity to talk to the physician about the resident's wishes regarding EOL treatment (Table 3).

The Differences Between LTCF Types

We observed an interaction between the country and the LTCF type in the model predicting FPPFC score. In Poland, the FPPFC score was significantly higher in institutions where physicians were employed on-site compared to LTCFs with off-site physicians (1.9 vs 1.5, respectively; $P = .002$) (Supplemental Table 1). In contrast, in Italy, the quality of communication with physicians was higher in LTCFs with off-site physicians than in LTCFs with on-site physicians (2.4 vs 1.9, respectively; $P = .023$). In the Netherlands, we did not find significant differences in respect to the type of institution. In other countries, only 1 type of LTCF existed, not allowing for such comparisons. When the LTCF types were considered separately, an analysis showed no statistically significant country differences in FPPFC scores in LTCFs with on-site physicians. On the contrary, in LTCFs served by off-site GPs, the quality of communication with a physician differed between countries significantly and was the highest in Italy and the Netherlands and the lowest in Finland and Poland (Figure 2).

Discussion

In our study, we focused on EOL communication concerning LTCF residents and asked the relatives most involved in care about their perceptions of this communication with the treating physician in the last phase of the resident's life. In 5 of 6 countries, the overall quality of EOL communication with physicians has been evaluated by the relatives as good (over the average 1.5 points on a scale of 0–3), but in most aspects it still needs some improvement. Our study showed that in all countries, relatives of deceased LTCF residents

retrospectively appraised the perception of EOL communication the highest in terms of being informed about the condition of the resident, the possibility of asking questions about the resident's care, and feeling understood and listened to by the physician. On the other hand, the respondents were most often dissatisfied with lack of communication by the physician about the resident's wishes for medical treatment when approaching death. They assessed physicians' assistance in understanding what he or she was saying to relatives about the possible course of a resident's dying as the second lowest.

The new report of the UK's Royal College of Physicians highlighted 3 types of barriers for GPs to talk about death: culture, confidence, and practicalities. There are still many physicians who do not feel confident to initiate conversations about future care and death.¹⁹ They also may have problems with recognition of the terminal phase of an LTCF resident's life as showed by Oosterveld-Vlug et al, who pointed out substantial variation between countries in regard to this (63% of residents in Italy to 80% in the Netherlands were properly diagnosed as dying).²⁰ In the physicians' opinion, it is easier to recognize the last phase of disease in cancer patients than in dementia or chronic disease in order to offer advance care planning (ACP).^{21,22} In our study, the prevalence of dementia among dying LTCF residents was much higher (up to 84.1% in Finland) than cancer (from 5.3% in England to 14.4% in Finland).

Most of the data on professional under- and postgraduate education in palliative medicine is quite diverse among the studied countries. There are significant differences between universities in terms of curricula of palliative medicine offered by them. According to the EAPC Atlas of Palliative Care and other sources, all the countries participating in our study reported availability of undergraduate and/or postgraduate courses in palliative medicine.^{23–29} However, information about whether they include training in EOL communication is lacking (see [Supplemental Table 3](#) for a summary of educational curricula in palliative medicine in the studied countries).

Therefore, physicians providing care for residents in LTCFs need more education on EOL communication.³⁰ The PACE "Steps to Success" training program is among several educational interventions focused on improving ACP by early initiation of discussions and planning future care between LTCF staff (nurses, care assistants, physicians) and residents and/or their relatives.³¹ Teaching staff to improve skills in EOL communication and ACP is especially important, because it has been shown to have an impact on the quality of EOL care, relatives' and patient's satisfaction, and reduction of anxiety, depression, and stress in relatives.^{32–34}

Based on data from Italy, the Netherlands, and Poland, we found a relatively high quality of EOL communication in the LTCFs with on-site physicians ([Figure 2](#)). It did not differ significantly between these 3 countries and possibly might be explained by relatively easy access to the physician, who is employed in the facility and is a stable member of the staff.¹¹ In comparison, the FPPFC scores in LTCFs served by GPs varied greatly between countries, with the highest values in Italy and the Netherlands and the lowest in Finland and Poland.

In Finland, it may reflect the organizational style that puts the main emphasis on nursing by increasing the role of nurses in such settings.³⁵ Nurses constitute almost 95% of care staff in these LTCFs (68.7% licensed practical nurses and 26.4% registered nurses).³⁶ Therefore, they are the primary staff members to communicate with residents' relatives and discuss EOL issues. Another barrier to good communication with physicians might be that according to our study, only 24.8% of the residents in Finland were treated by the same physician before and after admission to an LTCF. According to Steinhäuser et al, relatives of LTCF residents indicated receiving care from a resident's personal physician as the one of the most important aspects of EOL

care.⁷ Biola et al also showed that familiarity with a physician's name is significantly associated with a higher FPPFC score.¹³

In Poland, on-site physicians were removed from some LTCFs in 1999 and exchanged for off-site GPs, thus not ensuring continuity of care with the same physician before and after a resident's admission to the institution.³⁷ This may explain why, in our study, the percentage of residents treated by the same physician was the lowest in Poland (10.2% vs 67.7% in Belgium and 48.8% in Italy).

In Italy, there is no formal provision of palliative care to LTCF residents, although this is changing. For example, the local government of the Lombardia region (25% of LTCF beds in Italy) has adopted a resolution on implementation of general palliative care services into LTCFs that includes providing appropriate training for physicians.^{38,39}

In the Netherlands, relatives' perception of the quality of EOL communication with physicians was high, with no significant differences between LTCF types. However, both certified elderly care physicians and GPs receive training in communication with residents. Moreover, the specialist training program for elderly care physicians includes ACP.^{24,40} Thus, palliative medicine education of physicians may have an important meaning for high-quality EOL communication.

Strengths and Limitations

This is the first multicenter study of a large sample of relatives of deceased LTCF residents comparing their perceptions of quality of EOL communication with treating physicians. The study employed rigorous methods with a random sample selection. However, its retrospective and cross-sectional design brings some limitations. The relatives assessed communication with a physician sometime after the death of a close kin, so they might report it with recall bias. We applied a 3-month recall period based on evidence that it is a commonly accepted approach in EOL care research.^{41–44} We encountered some difficulties with identifying residents' relatives, low social acceptance to approach bereaved people for research purposes (in England, only 22.8% respondents answered), and ethical limitations in repetition of the invitation to the study (only 1 reminder in Poland resulted in a final 45.9% response rate). Nevertheless, we have reached an overall sufficient response rate (58.1%) for mailed questionnaires. Moreover, the nonresponse analysis based on the characteristics of deceased residents for the relatives who did and did not respond showed no significant differences, except for resident's sex and place of death. In this article, we focused on differences in FPPFC scale scores between countries and facility types. However, these findings need a more in-depth analysis of other factors associated with FPPFC, for example, the relative's, physician's, and resident's characteristics.

Conclusions and Implications

The results of our research indicate an important issue that concerns communication between a physician and a relative of a resident at the end of life. In this respect, despite the differences between countries, in each of them the most neglected area of communication is conversation about the patient's wishes for treatment when he or she cannot decide on it. Therefore, we suggest physicians working in LTCFs improve their communication skills on EOL care issues. The organizational support from LTCF managers is also extremely important to enable physicians to regularly participate in peer group meetings, which should help to enhance their skills in EOL care.

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Supplementary Data

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References

- Carter G, McLaughlin D, Kernohan WG, et al. The experiences and preparedness of family carers for best interest decision-making of a relative living with advanced dementia: A qualitative study. *J Adv Nurs* 2018;74:1595–1604.
- Winn P, Cook JB, Bonnel W. Improving communication among attending physicians, long-term care facilities, residents, and residents' families. *J Am Med Dir Assoc* 2004;5:114–122.
- Hudson P, Payne S. Family caregivers and palliative care: Current status and agenda for the future. *J Palliat Med* 2011;14:864–869.
- Levin TT, Moreno B, Silvester W, Kissane DW. End-of-life communication in the intensive care unit. *Gen Hosp Psychiatry* 2010;32:433–442.
- Sinuff T, Dodek P, You JJ, et al. Improving end-of-life communication and decision making: The development of a conceptual framework and quality indicators. *J Pain Symptom Manage* 2015;49:1070–1080.
- Heyland DK, Dodek P, Rocker G, et al. What matters most in end-of-life care: Perceptions of seriously ill patients and their family members. *CMAJ* 2006;174:627–633.
- Steinhauser KE, Christakis NA, Clipp EC, et al. Factors considered important at the end of life by patients, family, physicians, and other care providers. *JAMA* 2000;284:2476–2482.
- Hinkle LJ, Bosslet GT, Torke AM. Factors associated with family satisfaction with end-of-life care in the ICU. *Chest* 2015;147:82–93.
- Sloane PD, Zimmerman S, Hanson L, et al. End-of-life care in assisted living and related residential care settings: Comparison with nursing homes. *J Am Geriatr Soc* 2003;51:1587–1594.
- Williams SW, Williams CS, Zimmerman S, et al. Emotional and physical health of informal caregivers of residents at the end of life: The role of social support. *J Gerontol B Psychol Sci Soc Sci* 2008;63:S171–S183.
- Shield RR, Wetle T, Teno J, et al. Physicians "missing in action": Family perspectives on physician and staffing problems in end-of-life care in the nursing home. *J Am Geriatr Soc* 2005;53:1651–1657.
- Hanson LC, Danis M, Garrett J. What is wrong with end-of-life care? Opinions of bereaved family members. *J Am Geriatr Soc* 1997;45:1339–1344.
- Biola H, Sloane PD, Williams CS, et al. Physician communication with family caregivers of long-term care residents at the end of life. *J Am Geriatr Soc* 2007;55:846–856.
- Boogaard JA, Werner P, Zisberg A, van der Steen JT. Examining trust in health professionals among family caregivers of nursing home residents with advanced dementia. *Geriatr Gerontol Int* 2017;17:2466–2471.
- Evans N, Costantini M, Pasman HR, et al. End-of-life communication: A retrospective survey of representative general practitioner networks in four countries. *J Pain Symptom Manage* 2014;47:604–619.e3.
- Van den Block L, Smets T, van Dop N, et al. Comparing Palliative Care in Care Homes Across Europe (PACE): Protocol of a cross-sectional study of deceased residents in 6 EU countries. *J Am Med Dir Assoc* 2016;17:566.e1–566.e7.
- Zimmerman S, Cohen L, van der Steen JT, et al. Measuring end-of-life care and outcomes in residential care/assisted living and nursing homes. *J Pain Symptom Manage* 2015;49:666–679.
- van Soest-Poortvliet MC, van der Steen JT, Zimmerman S, et al. Selecting the best instruments to measure quality of end-of-life care and quality of dying in long term care. *J Am Med Dir Assoc* 2013;14:179–186.
- Royal College of Physicians. Talking about dying: How to begin honest conversations about what lies ahead. 2018: Available at: <https://www.rcplondon.ac.uk/projects/outputs/talking-about-dying-how-begin-honest-conversations-about-what-lies-ahead>. Accessed January 14, 2019.
- Oosterveld-Vlug MG, Pasman HRW, ten Koppel M, et al. Physician visits and recognition of residents' terminal phase in long-term care facilities: Findings from the PACE cross-sectional study in 6 EU countries. *J Am Med Dir Assoc* 2019;20:696–702.
- Lovell A, Yates P. Advance care planning in palliative care: A systematic literature review of the contextual factors influencing its uptake 2008–2012. *Palliat Med* 2014;28:1026–1035.
- De Vleminck A, Pardon K, Beernaert K, et al. Barriers to advance care planning in cancer, heart failure and dementia patients: A focus group study on general practitioners' views and experiences. *PLoS One* 2014;9:e84905.
- Centeno C, Lynch T, Donea O, et al. EAPC Atlas of Palliative Care in Europe 2013–Full edition. Milan: EAPC Press; 2013.
- Koopmans RTCM, Pellegrom M, van der Geer ER. The Dutch move beyond the concept of nursing home physician specialists. *J Am Med Dir Assoc* 2017;18:746–749.
- Walker S, Gibbins J, Paes P, et al. Palliative care education for medical students: Differences in course evolution, organisation, evaluation and funding: A survey of all UK medical schools. *Palliat Med* 2017;31:575–581.
- Centeno C, Bolognesi D, Biasco G. Comparative analysis of specialization in palliative medicine processes within the World Health Organization European Region. *J Pain Symptom Manage* 2015;49:861–870.
- Carrasco JM, Lynch TJ, Garralda E, et al. Palliative care medical education in European universities: A descriptive study and numerical scoring system proposal for assessing educational development. *J Pain Symptom Manage* 2015;50:516–523.e2.
- Lehto JT, Hakkarainen K, Kellokumpu-Lehtinen P-L, Saarto T. Undergraduate curriculum in palliative medicine at Tampere University increases students' knowledge. *BMC Palliat Care* 2017;16:13.
- Singler K, Holm EA, Jackson T, et al. European postgraduate training in geriatric medicine: Data of a systematic international survey. *Aging Clin Exp Res* 2015;27:741–750.
- Katz PR. An international perspective on long term care: Focus on nursing homes. *J Am Med Dir Assoc* 2011;12:487–492.e1.
- Smets T, Onwuteaka-Philipsen BBD, Miranda R, et al. Integrating palliative care in long-term care facilities across Europe (PACE): Protocol of a cluster randomized controlled trial of the "PACE Steps to Success" intervention in seven countries. *BMC Palliat Care* 2018;17:47.
- Detering KM, Hancock AD, Reade MC, Silvester W. The impact of advance care planning on end of life care in elderly patients: Randomised controlled trial. *BMJ* 2010;340:c1345.
- Sleeman K. End-of-life communication: Let's talk about death. *J R Coll Physicians* 2013;43:197–199.
- Hwang SS, Chang VT, Alejandro Y, et al. Caregiver unmet needs, burden, and satisfaction in symptomatic advanced cancer patients at a Veterans Affairs (VA) medical center. *Palliat Support Care* 2003;1:319–329.
- Genet N, Boerma WGW, Kroneman M, et al. Home Care across Europe: Current Structure and Future Challenges. Brussels: European Observatory on Health Systems and Policies; 2012.
- Smets T, Pivodic L, Piers R, et al. The palliative care knowledge of nursing home staff: The EU FP7 PACE cross-sectional survey in 322 nursing homes in six European countries. *Palliat Med* 2018;32:1487–1497.
- Golinowska S. The long-term care system for the elderly in Poland. ENEPRI research report no. 83. 2010: Available at: [http://www.ancien-longtermcare.eu/sites/default/files/ENEPRI%20RR%20No%2083%20\(ANCIEN%20-%20Poland\).pdf](http://www.ancien-longtermcare.eu/sites/default/files/ENEPRI%20RR%20No%2083%20(ANCIEN%20-%20Poland).pdf). Accessed January 14, 2019.
- Tediosi F, Gabriele S. The long-term care system for the elderly in Italy. ENEPRI research report no. 80. 2010: Available at: http://www.ancien-longtermcare.eu/sites/default/files/ENEPRI%20_ANCEIEN_%20RR%20No%2080%20Italy%20edited%20final.pdf. Accessed January 14, 2019.
- Coda Moscarola F. Long-term care workforce in Italy. Supplement C to NEUJOBS working paper 2013: Available at: http://www.neujobs.eu/sites/default/files/publication/2014/02/LTC_workforce_Italy_final_D12.2.pdf. Accessed January 14, 2019.
- Hendriks SA, Smalbrugge M, Deliens L, et al. End-of-life treatment decisions in nursing home residents dying with dementia in the Netherlands. *Int J Geriatr Psychiatry* 2017;32:e43–e49.
- De Gendt C, Bilsen J, Vander SR, Deliens L. Advance care planning and dying in nursing homes in Flanders, Belgium: A nationwide survey. *J Pain Symptom Manage* 2013;45:223–234.
- Vandervoort A, Van den Block L, van der Steen JT, et al. Nursing home residents dying with dementia in Flanders, Belgium: A nationwide postmortem study on clinical characteristics and quality of dying. *J Am Med Dir Assoc* 2013;14:485–492.
- Pivodic L, Harding R, Calanzani N, et al. Home care by general practitioners for cancer patients in the last 3 months of life: An epidemiological study of quality and associated factors. *Palliat Med* 2016;30:64–74.
- Van den Block L, Deschepper R, Bossuyt N, et al. Care for patients in the last months of life. *Arch Intern Med* 2008;168:1747.